The Kentucky Colon Cancer Screening Program Advisory Committee Annual Report July 2010 through June 2011

This report was prepared by

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Division of Prevention and Quality Improvement
Chronic Disease Prevention Branch in Collaboration with
The Kentucky Colon Cancer Screening Program Advisory Committee

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Message from the Kentucky Colon Cancer Screening Program Advisory Committee

In 2008, the Kentucky General Assembly enacted KRS 214.540 which provided for the establishment of a state-wide colon cancer screening program. According to the legislation, the Kentucky Colon Cancer Screening Program (KCCSP) is to be established for three purposes:

- 1) Increasing colon cancer screening
- 2) Reducing morbidity and mortality from colon cancer
- 3) Reducing the cost of treating colon cancer among citizens of the Commonwealth

Colon cancer is a significant health problem in Kentucky - it is the second leading cause of cancer death when rates for men and women are combined. Despite our successes over the years in raising our screening rates, over 30% of Kentuckians are still not screened for colon cancer according to the guidelines. Many colon cancers can be prevented by removing polyps before they develop into cancer.

As part of the KRS 214.544 legislation, a Kentucky Colon Cancer Screening Program Advisory Committee (KCCSPAC) was assembled to provide recommendations for the overall implementation and conduct of the Kentucky Colon Cancer Screening Program. Currently, over twenty-five representatives from organizations addressing colon cancer and screening activities provide consultation and oversight for the public awareness program as well as offering indirect support to the development of the program.

Efforts to move forward on the three purposes are incremental and can only be accomplished in partnership with others. Members of the advisory committee continue to develop innovative and grassroots projects to address colon cancer screening in our state. In the 2010 Special Session, the General Assembly allocated \$200,000 of coal severance funds to support colon cancer prevention and screening efforts in four counties: Floyd, Letcher, Martin, and Pike.

The coalition of partners comprising the Advisory Committee continue to move forward in their collaborative efforts to reduce the high rates of colon cancer incidence and mortality in Kentucky, through screening, early detection, and community outreach initiatives.

This annual report highlights this past year's effort and also describes the critical need to move forward with increased preventive screening messaging and access for those Kentuckians who have the most burden of colon cancer incidence and mortality.

John M. Bennett, MD, MPH

Chair, Kentucky Colon Cancer Screening Program Advisory Committee

Executive Summary

This annual report of the Kentucky Colon Cancer Screening Program Advisory Committee for July 2010 through June 2011 is mandated by KRS 214.544 to provide an implementation and outcome update as well as recommendations to the Legislative Research Commission (LRC), the Interim Joint Committee on Health and Welfare, the Interim Joint Committee on Appropriations and Revenue, the Governor, the Secretary of the Cabinet for Health and Family Services (CHFS), and the Commissioner of the Department for Public Health, as well as being available to the general public.

Section I: Kentucky Colon Cancer Screening Advisory Committee and Program Support

• Overview of the Kentucky Colon Cancer Screening Advisory Committee

Section II: The Problem of Colorectal Cancer in Kentucky: An Overview of Data

- Incidence and Mortality Rates
- Screening Rates and Barriers to Colon Cancer Screening
- Disparate Populations

Despite successes over the years in raising colonoscopy screening rates to 63.7%, Kentucky still lags behind the national rate of 65.3%- based on 2010 KY and the Centers for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System (BRFSS) data. Lower screening rates lead to later stage diagnosis of colon cancer. A brief overview of current data related to incidence, mortality, screening, and the burden experienced by disparate populations are found in Section II. This data illustrates the high burden of colon cancer found in Kentucky. For the purposes of this document, "colon cancer" will be used interchangeably throughout this document with "colorectal cancer" or CRC as both phrases are medically and academically acceptable terminology.

Section III: Financial Impact of Colorectal Cancer in Kentucky

Colorectal cancer is a costly yet highly preventable disease. Investment in clinical preventive services has been proven cost-effective and can reduce the burden of incidence and mortality from colon cancer in Kentucky. The average charge for a single hospital stay in Kentucky in 2010 with a primary diagnosis of colorectal cancer was \$46,105 and totaled \$98,666,400 for the year. Although Medicare is the primary payer for the majority of cases, Kentucky Medicaid shares a portion of providing care for low-income citizens with colon cancer. There is also a financial burden to employer-sponsored insurance and self-pay citizens.

Section IV: Kentucky Colon Cancer Screening Advisory Committee- Partnership Efforts

• Awareness, Education, and Outreach Efforts of Partner Organizations

The Kentucky Colon Cancer Screening Advisory Committee is comprised of diverse stakeholders who all share the vision of improving colon cancer screening rates for Kentucky citizens in an effort to aid early detection, decrease mortality, improve health and effect cost-savings for individuals in addition to insurers, employers, the healthcare system, and government programs. A summary of major efforts is provided.

Section IV: Education and Outreach related to the Kentucky Cancer Program

The Kentucky Cancer Program, funded through the General Assembly and administered through the University of Kentucky and the University of Louisville, continues to implement a state-wide education and awareness campaign, "Targeted Colon Cancer Outreach Program" (TCCOP). This program includes many community and individual level interventions in an effort to increase colon cancer screening throughout the state.

I. Kentucky Colon Cancer Screening Advisory Committee and Program Support

The Kentucky Colon Cancer Screening Program (KCCSP) and the Kentucky Colon Cancer Screening Advisory Committee (KCCSAC) were developed in 2008 by passage of House Bill 415 which was codified into law as KRS 214.540-544 (Appendix A). The advisory committee provides oversight for a colon cancer screening public awareness campaign in Kentucky and provides this annual report on implementation and outcomes to the appropriate groups as noted in KRS 214.544 Section 7. The makeup of the advisory committee includes members representing organizations, agencies and survivors of colon cancer who are working toward decreasing the incidence, mortality, and burden of colon cancer in Kentucky.

The KCCSAC meets on the third Thursday of each month at 1:30 pm in the Capitol Annex. These meetings began officially in July of 2008 and minutes are recorded and accessible by public record request through the Kentucky Department for Public Health (KDPH), Division of Prevention and Quality Improvement (DPQI). Each monthly meeting is dedicated to the development of the Kentucky Colon Cancer Screening Program, public awareness campaign, and development of recommendations that will move the program forward. Usual agenda items of these meetings include: presentations with current data on incidence and mortality from the Kentucky Cancer Registry; reports from the Kentucky Cancer Program; review and updates to the program manual; best practice models for outreach, materials, and links on the KDPH website (http://chfs.ky.gov/dph/ColonCancer.htm); and discussion of potential funding sources.

The future direction of the KCCSAC continues to focus on developing a sustainable infrastructure for the Kentucky Colon Cancer Screening Program. According to the provisions of KRS 214.540, the program is established for the purposes of:

- (a) Increasing colon cancer screening;
- (b) Reducing morbidity and mortality from colon cancer; and
- (c) Reducing the cost of treating colon cancer among citizens of the Commonwealth.

Program staff support is provided by the Kentucky Department for Public Health. KDPH is collaborating with member organizations of the KCCSAC as required by statute to develop the public awareness campaign, a data collection system and an outreach and screening program. The Kentucky Cancer Program and the Kentucky Cancer Consortium provide expertise and connection to coalitions and networks of professional and lay persons working to decrease the burden of cancer in Kentucky.

KDPH will also continue to work on integrated cancer screening and prevention efforts with the Kentucky Women's Cancer Screening Program (KWCSP) as well as other programs within the Health Care Access Branch (HCAB), and Chronic Disease Prevention Branch in the Division of Prevention and Quality Improvement and with other external partners. Providers and partners who address the needs of the uninsured, such as the local health departments (LHD) and the Federally Qualified Health Centers (FQHC), can provide outreach to high-need populations. This collaborative effort will maximize outreach, avoid duplication of services, and reinforce consistent messaging.

II. The Problem of Colorectal Cancer In Kentucky: An Overview of Data

Introduction

Colorectal cancer (CRC) is common, costly, and most importantly, highly preventable. CRC generally affects those 50 years old and older. It is the second most commonly diagnosed invasive cancer after lung cancer (for both males and females combined) and is responsible for high age-adjusted mortality rates as a result¹. Despite the fact that there are very effective screening tests for colorectal cancer, many eligible Kentuckians still do not receive these screening tests.

In terms of the economic impact, the medical and societal costs of CRC are substantial². In addition to decreasing mortality rates by finding colon cancer in its pre-cancerous stage, screenings can also significantly reduce the societal financial burden associated with treatment²⁻⁴. Colon cancer screening strategies have been found to be "cost effective compared to no screenings" by the U.S. Preventive Services Task Force (USPSTF) as well as having "high-impact on colon cancer burden"³⁻⁵.

Most colon cancers develop from a type of non-cancerous growth in the colon and rectum called an adenomatous polyp. Detecting and removing polyps by screening asymptomatic, age eligible people can actually prevent the disease from occurring.

Depending on the type and stage of when CRC is detected and other individual patient characteristics, the treatment protocol may include surgery, chemotherapy, and/or radiation³⁻⁴. In addition to active treatment, maintenance follow-up and/or palliative care contributes to the overall medical costs of not finding the cancer early³⁻⁴. Regardless of the treatment methodology, treatment costs can range from \$30,000 to \$120,000 depending upon the stage of the cancer when diagnosed³⁻⁴.

This section of the report will review the key data on CRC in Kentucky, including the incidence and mortality cases, utilization of age appropriate screening tests, and barriers to screening. Data comparing Kentucky with the nation will also be reviewed as well as highlighting disparities within Kentucky.

Kentucky Colorectal Cancer Data Compared to the Nation

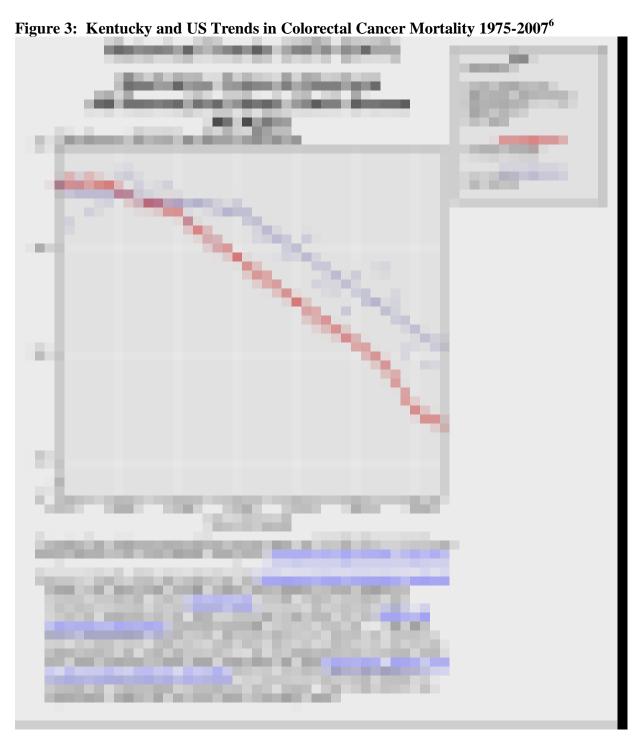
The map below shows the incidence rate of CRC for each state. For the years 2004 to 2008 combined, the national age-adjusted CRC incidence rate was 47.6 per 100,000 compared to the Kentucky age-adjusted rate of 55.7 per 100,000 population⁶. In fact, it is important to note that this data shows that Kentucky is tied with North Dakota as having the highest incidence of CRC in the nation¹. The map shows eight states, including Kentucky, colored red. These states have the highest rates in the nation ranging from 52.7 to Kentucky's high of 55.7 per 100,000⁶. This clearly illustrates the challenge facing Kentucky in addressing this common, costly, preventable form of cancer.

Figure 1: Incidence Rates of Colorectal Cancer 2004-2008⁶

The next map is the age-adjusted mortality rate due to CRC in each state for the combined years 2004-2008. The national mortality rate for CRC for those years combined is **17.1 per 100,000** while the rate for **Kentucky is the fourth highest in the nation at 20.1 per 100,000**^{1,6}.



Figure 3 below shows the comparison between Kentucky and the nation for colorectal cancer mortality. Since 1980, the mortality rate from colorectal cancer has been steadily declining both in the United States and in Kentucky. However, the **rate of decline is much slower in Kentucky compared to the U.S.**, with Kentucky continuing to maintain a gap in mortality rates that is widening in recent years⁶⁻⁷.

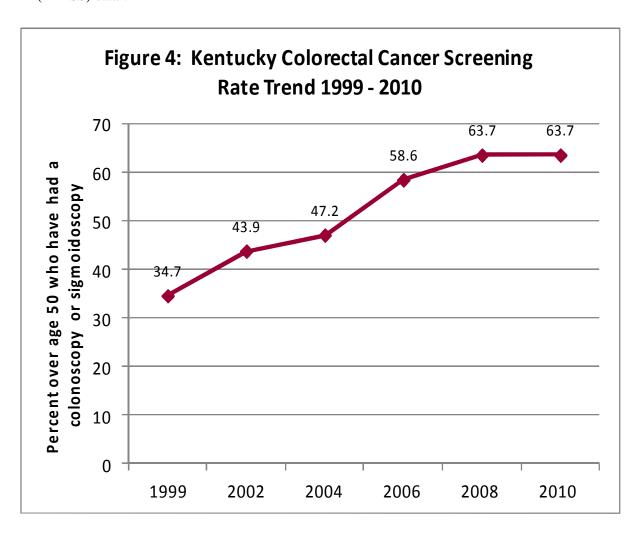


Colorectal Cancer in Kentucky

Screening Rates for Colorectal Cancer

For Kentucky to be successful in reducing the number of deaths due to colorectal cancer, it is necessary to ensure that Kentuckians receive appropriate screening based on their age and risk factors. The CDC states that "when colorectal cancer is found early and treated, the 5-year relative survival rate is 90%; however, because screening rates are low, less than 40% of colorectal cancers are found early."

Figure 4 below shows the trend for Kentucky in the percentage of those aged 50 and older who have been screened for colorectal cancer using a sigmoidoscopy or colonoscopy. Kentucky has made significant progress since 1999 with increasing colorectal cancer screening rates; however, there is still much work to be done. The **2010 screening rate for Kentucky is 63.7%, lagging behind the national rate of 65.3%** based on the 2010 KY and CDC Behavioral Risk Factor Surveillance System (BRFSS) data⁹.



Disparities in Colorectal Cancer Screening

Table 1 below shows the percentage of Kentuckians aged 50 and older who have <u>never been screened</u> for colorectal cancer using either a sigmoidoscopy or a colonoscopy. Overall, slightly more than a third of Kentuckians who meet the age criteria have not been screened (36.3%). However, the data clearly shows that the rate of <u>not being screened</u> is much higher for those with lower levels of education and lower income levels¹⁰.

Fully half (50.5%) of those with less than a high school education remain unscreened compared to 25% of college graduates. Similarly, 48.5% of those with incomes under \$15,000 per year are unscreened compared to 30.2% of those with incomes over \$50,000 per year.

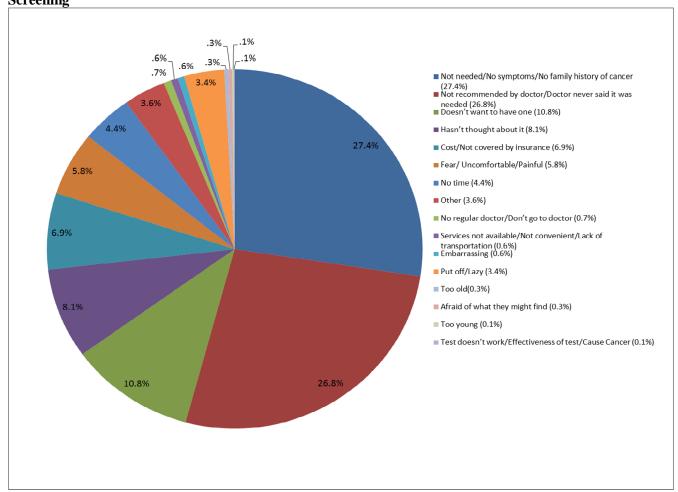
Table 1: Percent of Kentucky Adults aged 50+ who Have Never had a Sigmoidoscopy or Colonoscopy (2010 BRFSS)						
Level of Education	Percent (%)		Household Income	Percent (%)		
Less than High School	50.5		< \$15,000	48.5		
High School Graduate	39.8		\$15,000- 24,999	38.7		
Some Post High School	35.0		\$25,000- 34,999	35.8		
College Graduate	25.0		\$35,000- 49,999 \$50,000+	34.5 30.2		
All KY	36.3		All KY	36.3		

Barriers to Colon Cancer Screening in Kentucky

In 2008, an optional question was added to the Kentucky BRFSS Survey to gain insight into reasons why Kentuckians are not having a preventive colon cancer screening test. This BRFSS data was analyzed and distributed by the Kentucky Department for Public Health to partners who began disseminating it further and incorporating it into their work plans to address the barriers. Some of the most common reasons given were: not needed/no symptoms/no family history of cancer, 27.4%; not recommended by doctor/doctor never said it was needed, 26.8%; doesn't want to have one, 10.8%; hasn't thought about it, 8.1%; cost/not covered by insurance, 6.9%. (See **Figure 5**)¹⁰.

In response to this information, numerous members of the Colon Cancer Screening Advisory Committee focused on provider recommendation, the second most reported reason for never having a colon cancer screening: "Not recommended by doctor/Doctor never said it was needed". As a method to educate providers, Dr. John M. Bennett, Dr. Sarojini Kanotra, Dr. Jennifer Redmond, Susan Reffett, RN, and Sue Thomas-Cox, RN submitted the collaboratively written article, "Barriers to Colon Cancer Screening in Kentucky" to the Journal of the Kentucky Medical Association which was published in March 2011¹¹. This article reviewed the data on colorectal cancer in Kentucky and encouraged providers to work with their patients to increase screening referrals and patient compliance.

Figure 5: What is the most important reason you have <u>never</u> had a Sigmoidoscopy or Colonoscopy? KY BRFSS 2008- State Added Question Regarding Barriers to Colon Cancer Screening



Disparities in the Incidence of Colorectal Cancer in Kentucky

When examining gender, race, and geographic location in terms of disparities, Kentucky has higher rates of <u>colorectal cancer incidence</u> in all categories compared to the rest of the nation. In Kentucky, males overall have a larger burden of colorectal cancer incidence than females. The disparity in race is especially prominent for black males who have a much higher rate than their white counterparts. Black females also experience higher incidence rates than white females. In addition, residents of Kentucky's Appalachian counties have a higher incidence rate than the rest of the state and the nation overall.

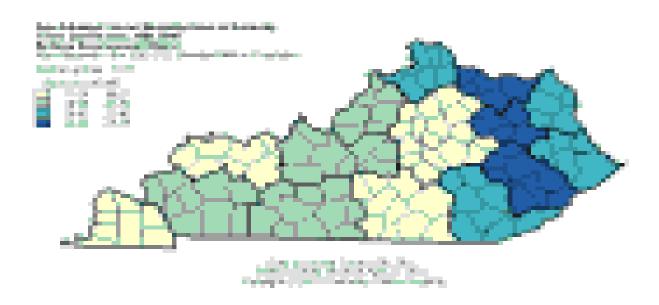
Table 2: Kentucky and US Colorectal Cancer Age A Incidence Rates per 100,000, 2004-2008					•	
Population	Males		Females		Total	Total
	U.S. ¹	KY^{12}	U.S. ¹	KY ¹²	US ¹	KY ¹²
All	52.7	66.65	39.7	47.40	47.6	55.74
Black	62.0	80.29	47.1	56.11	56.2	65.44
White	51.5	66.16	38.5	46.79	46.6	55.24
Appalachia		68.55		49.47		57.82
Non-Appalachia		65.85	-	46.59		54.89

Disparities in the Mortality of Colorectal Cancer in Kentucky

Similar to the differences seen in incidence rates, Kentucky also has significant disparities in terms of <u>colorectal cancer mortality</u> in all categories compared to the rest of the nation. The racial disparity is illustrated again for black males and females who have a much higher death rate from colorectal cancer than their white counterparts. The geographic disparity is again seen with residents of Kentucky's Appalachian counties having a higher mortality than the rest of the state and the nation overall.

	Table 3: Kentucky and US Age Adjusted Colorectal Cancer Mortality Rates 2004-2008					
Population	M	ales Females		Total	Total	
	U.S. ¹	KY ¹²	US ¹	KY ¹²	US ¹	KY ¹²
All	20.0	24.22	14.1	16.82	17.6	19.93
Black	29.1	32.11	19.7	24.04	24.7	27.31
White	19.5	23.94	13.7	16.47	17.1	19.61
Appalachia		25.35		17.62		20.90
Non-Appalachia		23.76		16.49		19.53

When examining differences in CRC mortality by Area Development Districts (ADDs), there are significantly higher rates in Kentucky's Appalachian region. The highest rates are seen in the Gateway, Kentucky River, and Buffalo Trace ADDs. The national average is 17.6¹².



Age Adjusted Colorectal Cancer Mortality Rates – Kentucky Area						
Development Districts 2004-2008 ¹²						
ADD District	Age Adjusted Rate	Total Deaths				
Gateway	23.33	96				
Kentucky River	22.96	142				
Buffalo Trace	22.52	72				
Northern Kentucky	22.46	426				
Cumberland Valley	21.69	276				
Big Sandy	21.58	177				
Fivco	20.82	167				
Lincoln Trail	20.76	259				
KIPDA	20.23	958				
Barren River	19.87	284				
Pennyrile	18.93	232				
Bluegrass	18.57	659				
Green River	17.61	211				
Lake Cumberland	17.1	209				
Purchase	17.04	220				
STATE OVERALL	19.93	4388				

III. Financial Impact of Colorectal Cancer in Kentucky

Colorectal cancer is usually treated with surgery, chemotherapy, and/or radiation, depending on the type of colorectal cancer, the stage of cancer at diagnosis, patient health, and other factors³. When treatment cost analysis for colon cancer has been conducted, initial and maintenance care is included and some studies include the cost of terminal treatment during the final six months of life. Regardless of the methodology, the general consensus is that treatment costs can range from \$30,000 to \$120,000 depending upon the stage of the cancer when diagnosed³⁻⁴. The U.S. Preventive Services Task Force (USPSTF) reviewed the main screening strategies for colorectal cancer and found that all were "cost effective compared with no screenings"³⁻⁵. Additional prevention studies identify colorectal cancer screening as a high-impact, cost-effective service⁴. The table below reflects inpatient discharges from Kentucky hospitals for primary diagnosis of colon cancer only.

Inpatient Discharges from Kentucky Hospitals with a Primary Diagnosis of Colorectal Cancer

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Kentucky	2006	2007	2008	2009	2010
Inpatient Discharges	2,179	2,212	2,093	2,158	2,140
Inpatient Charges	\$79,948,819	\$87,359,149	\$89,094,204	\$93,920,494	\$98,666,409

Office of Health Policy, Cabinet for Health and Family Services, Hospitalization Utilization Data

In 2010 there were 2,140 people admitted to Kentucky hospitals with a primary diagnosis of colorectal cancer. There were an additional 4,333 patients for whom the primary diagnosis was something other than colorectal cancer, but who had colorectal cancer at the time of admission. Total inpatient admission charges for patients with a <u>primary</u> diagnosis of colorectal cancer were \$98,666,400 for 2010 with averages charges for a single hospital stay of \$46,105. Based on data available from the Office of Health Policy, patients with colorectal cancer have an average inpatient length of stay of 8.23 days. Comparative data from the 2010 Kentucky Annual Hospital Utilization and Services Report indicates that overall average length of stay for patients with any diagnosis admitted to a Kentucky hospital is 4.7 days.

Because colorectal cancer tends to develop later in life, the primary payer for most of these costs is Medicare, which pays for approximately 59% of the total number of discharges annually. Prevention of colorectal cancer with screening and removal of polyps beginning at age fifty could substantially reduce the burden to Medicare.

Total inpatient charges to the Kentucky Medicaid system for patients with a <u>primary</u> diagnosis of colorectal cancer were \$5,557,155 for 2010. For Medicaid patients admitted to the hospital with <u>any diagnosis</u> and colorectal cancer, there is an additional \$11,749,004 in associated charges. These admissions could be for any diagnosis including complications such as nausea, vomiting or infection secondary to treatment.

Employers interested in saving money through prevention should review the numbers of persons covered by commercial insurance in their own organizations and determine if there have been admissions to the hospital for colorectal cancer. In Kentucky in 2010, there were 207 persons in the 50-64 age group admitted to the hospital for primary colorectal cancer, 113 persons in the over 65 age group and 111 in the 40-49 age group who were covered by <u>commercial insurance</u>. It is important to note that people are working longer due to the economy and this may account for some of the over 65 age group. Also of note are the 111 persons in the 40-49 age group. There are certain familial and genetic components

associated with colorectal cancer and any screening message should also address the importance of knowing family history. Persons with a family history of colon cancer are encouraged to begin screening earlier than age fifty working with their primary physician.

These numbers reflect only admissions and charges of inpatient care. There are substantial additional costs for chemotherapy and/or radiation therapy for treatment of colon cancer which are outpatient and are not reported to a primary database in Kentucky. There are additional indirect costs for employers which include days of work lost, worker replacement costs, and short and long-term disability. Costs are substantial to the person with colon cancer as well, with co-pays and out-of-pocket costs that sometimes range as high as 40 percent. For those with catastrophic coverage only, costs for outpatient treatment such as radiation and chemotherapy may not be covered. The loss of income for the time period of treatment, use of savings for health care which was intended for retirement, and second mortgages of homes are all substantial risks with a diagnosis of late stage colon cancer in order to fill payment gaps.

There is some good news in colon cancer screening for Kentucky over the past few years. There continues to be a substantial increase in colonoscopy usage for Kentucky residents ages 50 and older. The figures below represent outpatient service claim records including those records submitted by a hospital for an affiliated Ambulatory Facility and for some "Free-standing" Ambulatory Facilities. Free-standing ambulatory facilities only recently began submitting data to the Kentucky Office of Health Policy. Preventive screening codes, polyp removal, as well as some diagnostic procedure codes are utilized for this report.

These usage reports help to verify the increase over the past few years of self-reported colon cancer screening on the Kentucky BRFSS reports. These totals reflect colonoscopy procedures for 52,478 females which was an increase of 8,950 over 2009 reported procedures. There were 42,385 reported colonoscopies for males for an increase of 7,721 more than reported in 2009.

There is still some indication that men may be more reluctant than women to take time off from work or recognize the important message of prevention through screening. On a positive note, commercial insurance accounted for coverage of 50,479 colonoscopy procedures with 46,131 in the 50 to 64 age group. This is an increase from 43,410 total commercial colonoscopies in 2009 and 39,724 in the age group of 50-64 years of age. This improvement in early screening will continue to reduce cancer incidence and mortality rates through prevention.

Colonoscopy Procedures in Ambulatory Facilities in Kentucky Hospitals and for some "Free-standing" Ambulatory Facilities

Kentucky	2007	2008	2009	2010
Colonoscopy	51,624	62,978	78,192	94,865

Office of Health Policy, Cabinet for Health and Family Services, Outpatient Services Data

Although not required by federal regulations, the Kentucky Department for Medicaid Services has covered preventive colon cancer screenings for several years with a minimal patient co-pay of \$5.00. In 2010, there were 3,017 colonoscopies reported for persons covered by Medicaid in Kentucky. This is an increase from the 2009 total which was 2,585. Females with Medicaid represented two-thirds of the total which may be expected due to the current federal and state Medicaid eligibility regulations. However, there is more work to be done in messaging for persons with Medicaid regarding preventive screening for colon cancer.

In 2010 there were 1,838 self-pay colonoscopies. There were an additional 372 colonoscopies reported as charity. In the March 2011, Journal of the Kentucky Medical Association, Dr. Tucker, et al published findings that patients who lacked insurance had more than twice the odds of being diagnosed with advanced colorectal cancer¹³. The Small Area Health Insurance Estimates (SAHIE) utilizes data from the CDC and the U.S Census Bureau to estimate insurance coverage. The SAHIE 2009 report estimates there are over 100,000 uninsured persons ages 50-64 in Kentucky.

Many of the working poor do not qualify for Medicaid although they may be low income and would account for those who are self-pay or charity. Programs such as those in Pike, Floyd, Martin and Letcher have helped to cover these individuals, but there are still many uninsured Kentuckians who do not have access to prevention through colon cancer screening.

In summary, investment in clinical preventive services such as colon cancer screening has been proven to be cost effective and can reduce the burden of incidence and mortality from colon cancer in Kentucky. The KCCSP continues to move forward with education, outreach, and public awareness for prevention through screening. It is hopeful that partnerships and future funding will increase the reach to those who have never been screened and that those who cannot afford to be screened will gain access to the health system for preventive screening.

IV. Kentucky Colon Cancer Screening Advisory Committee-Partnership Efforts: Awareness, Education, and Outreach Efforts of Partner Organizations

American Cancer Society (ACS):

• Education and Outreach:

- Developed and disseminated an informational DVD on colon cancer screening to patients and caregivers throughout Kentucky
- o "How to increase colorectal cancer screening in your practice" manual was provided to primary care physicians through a variety of print and electronic distribution methods

Policy Efforts:

- O Continues to maintain its strong policy initiative focused on investment of preventive funding for cancer detection
- A strong volunteer presence was demonstrated with high attendance for the annual Lobby Day. This event engaged volunteers from across the state in one-on-one meetings with members of the General Assembly and Governor. ACS advocates helped introduce House Concurrent Resolution 94 in the 2011 Session. This proposal would officially create a Kentucky Cancer Survivors and Friend Caucus, a nonpartisan group of legislators from both the Senate and House who would work together on policy, regulation, and proposals that would help reduce the burden of cancer on patients and families. HCR 94 passed out of the House Health and Welfare committee and out of the House unanimously, but ran out of time for consideration in the Senate due to the short session. Representative Jim Glenn, whose wife recently passed away from colon cancer, was the lead sponsor. The bill served to help raise awareness of colon and other cancer issues in the General Assembly and when enacted, will ensure cancer and patient issues remain at the forefront of the agenda in Frankfort.

• Patient Support Services:

- o ACS Hope Lodge in Lexington continues to provide patient support services to colon cancer patients with over 200 nights of free lodging provided to colon cancer patients.
- Additionally, from Sept 2010-Aug 2011, the American Cancer Society Patient Services programs served over 9,000 Kentuckians; approximately 800 of those were patients with colon cancer. The patient service programs include transportation assistance, lodging resources, support groups and information.

Navigation Services:

 An on-site Patient Navigator Program was launched at the University of Kentucky Markey Cancer Center this past year, with the intent to connect cancer patients with ACS programs and services, as well as community resources. In several eastern Kentucky cancer centers, ACS opened volunteer staffed Cancer Resource Centers to address barriers to treatment and provide resources for underserved patients.

Cabinet for Health and Family Services (CHFS)- Kentucky Department for Public Health (KDPH):

• Data System and Website:

- O KDPH staff that included the Breast and Cervical Cancer epidemiologist, the Chronic Disease Prevention Epidemiologist, the CDPB manager, the Colon Cancer Screening program manager, the Office of Information Technology and the Pike County Health Department worked with a DrPH student from the University of Kentucky College of Public Health and the Kentucky Cancer Registry in developing and testing a data collection system that would be consistent with CDC requirements for reporting.
- o KDPH maintains and updates the state Colon Cancer Screening Program website with information including the annual report and education for the public, health educators and

- providers as well as links to additional partner organizations. http://chfs.ky.gov/dph/ColonCancer.htm
- CHFS and KDPH provide colon cancer screening, hospital admission and mortality surveillance via Behavioral Risk Factor Surveillance System, Vital Statistics, and Hospital Discharge Data.

• State Fair:

o KDPH organized three days for interactive display of the giant Educational Colon with over 6,000 people participating. There are two educational colons funded by KDPH through the CDC Preventive Health and Health Services Block Grant. One colon is housed at Louisville Metro Health Department and the other at Pike County Health Department. Volunteers included partners from the Colon Cancer Prevention Committee who were able to educate those who toured the interactive educational display. Participants over 50 years old were asked to complete a brief survey regarding whether they had been screened for colon cancer and identify any barriers to screening. These results have mirrored information gained from the Kentucky BRFSS survey.

• Program Resource Manual:

A program manual was developed in a collaborative effort between KDPH staff, the lead pilot site, Pike County Health Department, and advisory committee members.
 Communities who are starting screening programs utilize the templates, information and resources in this manual. The manual has been widely shared and is available on the KDPH Colon Cancer Screening Program website.

• Technical Assistance:

o KDPH provides ongoing technical assistance to local health departments and management for the development of colon cancer screening programs within the state including those receiving Coal Severance Funds.

• Worksite Wellness:

The Colon Cancer Screening Program Manager developed a collaborative effort with the State Wellness Director in the Kentucky Personnel Cabinet to host a special education day focused on Colon Cancer Screening Awareness for state employees in March of 2011. Tours of the interactive educational colon were available along with information explaining state employee health insurance benefits for preventive screening with minimal co-pay. Approximately 30,000 employees were exposed to the colon cancer screening awareness message. Some state government cafeterias displayed large posters explaining the benefits of colon cancer screening and "blue plate specials" to emphasize the "blue star" associated with colon cancer screening. A YouTube video explaining the educational colon and the importance of screening was created with the State Wellness Director, Dr. Whitney Jones, and other partners. This video is available on the KDPH Colon Cancer Screening Program website.

• Public Health Nurses Update:

In October of 2010, KDPH hosted a videoconference for public health nurses and health educators through the Workforce Development Branch TRAIN system regarding Clinical Updates on Colon Cancer Screening. TRAIN is available in all 58 local health departments with real time training availability, interactivity and webcasting for later use. This presentation is also available on the KDPH Colon Cancer Screening Program website.

Coal Severance Funds:

- During the 2010 Legislative Session, \$200,000 was allocated in the biennial budget of 2010-2012 for the counties of Floyd, Letcher, Martin, and Pike. Each county received \$50,000 for screening. Coal severance funds were used in these counties to implement colon cancer education and screening programs for disadvantaged individuals without insurance.
- As of June 2011, seventy-five persons had been screened using coal severance funding. As a result, one case of colorectal cancer was detected and polyps were removed from thirty-three individuals which had the potential to develop into cancer.
- It should be noted that Pike County's screening program has been active since 2007 using local tax dollars directed by their board of health. Since that time, 102 individuals have received a colonoscopy through Pike County's program. Of those screened, 35% had polyps that were removed, thus preventing the risk that they could develop into colorectal cancer. As of July 2011, Pike County already exhausted their funding allotment by screening forty persons; the remaining counties have not spent all of their allotment but anticipate doing so by June 30, 2012.
- In May 2011, Senate Chair Johnny Ray Turner and State Senator Ray Jones II, along with support from Colon Cancer Prevention Advisory Committee partners, sent a letter to all House and Senate members who represent a county that receives coal severance funding encouraging them to support a similar colon cancer screening program in their county by utilizing coal severance funding.

Colon Cancer Prevention Project (C2P2):

• Education and Outreach:

- O Produced its annual educational program, Catching a Killer: Colon Cancer Among Us. This fifth show is a documentary-style educational program focusing on patients' and families' stories and initially aired for Colon Cancer Awareness Month on March 24, 2011 on KET. As many as 25,000 watched this initial broadcast, and it has aired several subsequent times. Sponsors included the Preventive Health and Health Services Block Grant (PHHSBG) through KDPH, Louisville Metro Public Health and Wellness, Norton Cancer Institute and C2P2.
- One million copies of "Are You at Risk?" blue brochures have been disseminated. The brochure is an informational tool to teach people about the symptoms and risks of colon cancer, as well as screening.
- o The Colon Cancer Prevention Project had its fifth annual Walk Away from Colon Cancer & 5K Run in Louisville in August 2010. The event was the largest yet, with more than 600 survivors, patients, physicians and concerned members of the community.

Policy Efforts:

- O Collaborated with the state auditor, Crit Luallen, a colon cancer survivor and strong speaker on the issues of colon cancer screening and prevention. Dr. Whitney Jones and Ms. Luallen were featured on the *One to One with Bill Goodman* program on KET in March 2011. They discussed efforts to eliminate preventable colon cancer death by increasing screenings in Kentucky. The show aired on KET numerous times.
- O Collaborated with partners to draft a letter to all Senate leaders encouraging them to utilize coal severance funding for colon cancer screening programs in their counties.

• Awards and Recognition:

- C2P2 Founder, Dr. Whitney Jones, received the Laurels Award for Advocacy in March 2011.
 (The Prevent Cancer Foundation's Dialogue for Action uses the Laurels awards to recognize and celebrate innovators and leaders in the fight against colorectal cancer.)
- o The Colon Cancer Prevention Project has been invited to join the National Colorectal Council Roundtable (NCCRT), which is a national coalition of public, private, and voluntary organizations dedicated to reducing the incidence of and mortality from colorectal cancer in the U.S.

Colon Cancer Prevention Committee (CCPC) under the Kentucky Cancer Consortium:

• Education and Outreach:

- The focus of the Committee's activities has been discussing the first four barriers to colorectal screening as identified in the 2008 Kentucky BRFSS data. These barriers include (in order of significance by survey respondents):
 - Not needed/No symptoms/No family history (27.4%)
 - Not recommended by doctor/Doctor never said it was needed (26.8%)
 - Doesn't want to have one (10.8%)
 - Hasn't thought about it (8.1%)
- o Partners have discussed and shared how they are using this data to influence their work activities to be effective in addressing these barriers.
- CCPC members and Katie Bathje of the Kentucky Cancer Consortium have developed a Community Colorectal Cancer Educational Powerpoint for partners to use.

Kentucky Cancer Consortium (KCC):

- Policy and Environmental Systems Change:
 - O KCC was awarded in October 2010 a five-year grant to implement policies and systems changes around primary and secondary prevention activities found in the Kentucky Cancer Action Plan. One of the three policy initiatives that KCC is focused on with related partners includes increasing colorectal cancer screening rates by decreasing structural and/or financial barriers.

Kentucky Cancer Registry (KCR):

- Surveillance Data:
 - o KCR continues to present data related to colorectal cancer incidence, mortality, and screening rates to partner organizations, Advisory Committee members, legislative members, and the general public. In addition, special attention is focused on disparate populations. This emphasis on statistical evidence helps diverse partnerships determine their work plan activities. Data presentations also assure the dissemination of this important information.
 - KCR has continued to strengthen its working relationship with academic institutions, particularly with the University of Kentucky Markey Cancer Program and the University of Louisville Brown Cancer Center.

<u>Kentucky Colon Cancer Screening Program Advisory Committee Members and the Kentucky</u> Medical Association (KMA):

- Journal of the KMA- March 2011:
 - o For the second time, the KMA Journal devoted its entire March edition to colon cancer and screening. The first time occurred in 2009.
 - Advisory Committee members and partners submitted academic articles for publication in the journal and included a diverse writing group: Dr. Mel Bennett, Dr. Thomas Tucker, Dr. Jennifer Redmond, Susan Reffett, Sue Thomas-Cox, and Dr. Whitney Jones. In addition,

- Committee members collaborated with a number of other professionals including Dr. Sarojini Kanotra of DPH and Bin Huang and Eric Durbin of the Kentucky Cancer Registry.
- This journal included "Barriers to Colon Cancer Screening in Kentucky", "The Effect of Insurance on Stage at Diagnosis for Colorectal Cancer Patients in Kentucky" as well as an Introductory Letter, a Colorectal Cancer Screening Tip Sheet and a Snapshot of Colon Cancer.

Pike County/Eastern Kentucky Partnership Forum:

• Partnership Forum:

- o In collaboration with the Pike County Health Department, the Kentucky Cancer Program and the Colon Cancer Prevention Committee, KDPH provided funding through the Preventive Health and Health Services Block Grant for a fall forum which included presentations on data, best practices, Faces of Colon Cancer, survivor stories and input from community policy and decision makers.
- Eighty-four participants from across the state attended the forum. Among the most popular and useful aspects of the forum included networking opportunities and hearing from local health departments regarding their screening efforts.
- O The purpose of the partnership event was to share ideas, develop relationships for possible future collaborations as well as discuss what is working in increasing colon cancer screening rates among the uninsured and underinsured population in Kentucky.

V. Education and Outreach related to the Kentucky Cancer Program

KRS 214.544, Section 3.8. The Kentucky Cancer Program, jointly administered by the University of Kentucky and University of Louisville, shall establish a colon cancer screening education and outreach program in each of the state area development districts. The program shall focus on individuals who lack access to colon cancer screening.

The Kentucky Cancer Program (KCP) continued to coordinate the "Targeted Colon Cancer Outreach Program" (TCCOP) established in fall 2009. This evidence-based model focuses on raising awareness of colon cancer screening among all Kentuckians and sets the stage for participation in the state program once it is funded. KCP is working with District Cancer Councils (DCCs) and community partners across the state to implement a comprehensive "Targeted Colon Cancer Outreach Program" (TCCOP) in each of Kentucky's 15 area development districts (ADDs).

The initiative encourages community organizations and groups to coordinate their efforts and form partnerships. It provides a broad framework of possible strategies from which organizations can work, including media campaigns, distribution of educational materials and key messages, educational programs for the public and health care providers, and special initiatives such as "Dress in Blue Day." Reaching people who do not have access to screening is a program priority.

During the past year, funding for TCCOP activities was provided by the Centers for Disease Control and Prevention (through a supplemental grant to the KCC), and Kentucky Cancer Program. In-kind contributions/support were secured from hundreds of partners, including hospitals, clinics, pharmacies, universities and colleges, American Cancer Society, local health departments, Cooperative Extension Service offices, Area Health Education Centers, businesses, chambers of commerce, government agencies, public schools, churches, libraries, and individuals. These partners integrated colon cancer education and outreach into their existing services.

Highlights of these activities for the past year are summarized below. During Fiscal Year 2010-2011 District Cancer Council and Colon Cancer Committee meetings were held across the state with representatives of community organizations and groups focused on developing plans to implement TCCOP strategies and activities.

Public Awareness and Educational Materials

- Organizations/groups/businesses distributed over 86,000 posters, bookmarks and church bulletins containing key messages about colon cancer screening in all 120 counties.
- Over 61,000 promotional pieces and 27,300 educational materials were disseminated across the state.
- Local guides were developed by many KCP District Cancer Councils as a resource for individuals and organizations in locating colon cancer screening facilities in their community.

Dress In Blue Campaign

- Over 560 partners participated as part of a national campaign to raise awareness about screening.
- In addition to wearing blue on March 5, 2011, hundreds of special events and activities took place throughout Colon Cancer Awareness Month at worksites, hospitals, and businesses.

Educational Presentations

• The DCCs sponsored 70 educational programs targeting over 3,750 health care providers, social service organizations, businesses, and other community organizations and groups.

Regional and Small Media

- KCP distributed a toolkit containing tips for reaching the media, sample press releases, articles for newspapers and newsletters, print advertisements, and public service announcements. A new *Colonoscopy Fee Worksheet* was added to the kit to assist patients in estimating their out-of-pocket cost for a colonoscopy.
- DCC and community partners secured free publicity, including 106 television and radio shows, public service announcements, newsletter and newspaper articles. In addition, hundreds of organizations were provided e-mail messages and encouraged to share them with their networks and employees. Although challenging to track, it is estimated that at least 80,000 people were reached.

Special accomplishments:

- The KCP developed a special "Faces of Colon Cancer" photographic exhibit featuring nine survivors who shared their stories and encouraged others to get screened to prevent colon cancer. Working with DCCs in nine ADDs in central and eastern Kentucky, the exhibit was on display for a total of 130 days at 33 locations and reached an estimated 22,000 people with the life-saving message that colon cancer screening saves lives. A second exhibit was created and unveiled at the film preview event of "Catching a Killer" in Louisville. Featured among the survivors was State Auditor Crit Luallen.
- KCP received funding from the Kentucky Cancer Consortium to develop and pilot a new worksite wellness program to encourage employees at businesses across the state to get screened for colon cancer. During the campaign, activities and messages focused on the importance of getting screened for colon cancer were shared with 3,853 employees. Funds have been provided to expand the program to reach additional businesses and employees next year.
- KCP utilized the Kentucky Department for Public Health educational colon in Louisville and Western Kentucky. The giant inflatable colon was displayed at 9 locations where over 3,000 people toured the exhibit and 1,003 responded to a brief survey. The colon is an excellent way to work with local partners to increase awareness and provide education about the importance of screening.

Appendix A: Statutes and Administrative Regulations

214.540 Definitions for KRS 214.540 to 214.544 -- Establishment and limitation of Colon Cancer Screening Program.

- (1) As used in KRS 214.540 to 214.544:
- (a) "Department" means the Department for Public Health in the Cabinet for Health and Family Services; and
- (b) "Program" means the Colon Cancer Screening Program.
- (2) The Colon Cancer Screening Program is hereby established for the purposes of:
- (a) Increasing colon cancer screening;
- (b) Reducing morbidity and mortality from colon cancer; and
- (c) Reducing the cost of treating colon cancer among citizens of the Commonwealth.
- (3) The provisions of KRS 214.540 to 214.544 shall be limited to the amount of appropriations to the department for the Colon Cancer Screening Program.

Effective: July 15, 2008

History: Created 2008 Ky. Acts ch. 126, sec. 1, effective July 15, 2008.

214.542 Eligibility for Colon Cancer Screening Program -- Services provided -- Funding -- Data collection -- Administrative regulations.

- (1) The program shall provide colon cancer screening for uninsured individuals who are age fifty (50) to sixty-four (64) and other uninsured individuals determined to be at high risk for developing colon cancer.
- (2) Services provided under the program may be undertaken by private contract for services or operated by the department. The program may also provide referral services for the benefit of individuals for whom further examination or treatment is indicated by the colon cancer screening.
- (3) The department may accept any grant or award of funds from federal or private sources for carrying out the provisions of this section.
- (4) The department shall establish a data collection system to document the number of individuals screened, the demographic characteristics of the individuals screened, and the types of colon cancer screening tests performed under the program.
- (5) The department shall promulgate administrative regulations to implement the provisions of this section.

Effective: July 15, 2008

History: Created 2008 Ky. Acts ch. 126, sec. 2, effective July 15, 2008

214.544 Colon Cancer Screening Advisory Committee -- Membership -- Duties -- Annual report -- Colon cancer screening, education, and outreach programs.

- (1) A Colon Cancer Screening Advisory Committee shall be established within the Kentucky Cancer Consortium. The advisory committee shall include:
- (a) One (1) appointee appointed by the Speaker of the House;
- (b) One (1) appointee appointed by the President of the Senate;
- (c) The deputy commissioner of the Department for Public Health;
- (d) Two (2) at-large members appointed by the Governor;
- (e) The director of health initiatives for the mid-south division of the American Cancer Society;
- (f) The director of the Kentucky Cancer Program at the University of Kentucky;
- (g) The director of the Kentucky Cancer Program at the University of Louisville;
- (h) The director of the Kentucky Cancer Registry;
- (i) The director of the Colon Cancer Prevention Project;
- (j) The chair of Kentucky African Americans Against Cancer; and
- (k) The director of the Kentucky Cancer Consortium.

Members of the advisory committee shall be appointed for a term of four (4) years.

- (2) (a) Members appointed under subsection (1)(a) to (d) of this section shall be appointed as follows:
- 1. Members shall be appointed for a term of four (4) years, except as provided in subparagraph 2. of this paragraph;
- 2. The initial appointments shall be for a period of two (2) years; thereafter, the appointments shall be for a term of four (4) years; and
- 3. Members shall not serve more than two (2) terms of four (4) years.
- (b) Members serving under subsection (1)(e) to (k) of this section shall serve by virtue of their positions and shall not be subject to term limits.
- (3) The chair of the advisory committee shall be elected from the membership of the advisory committee to serve for a two (2) year term. A member of the advisory committee may designate an alternate to attend meetings in his or her place.
- (4) The advisory committee may add members from other organizations as deemed appropriate.
- (5) The advisory committee shall provide recommendations for the overall implementation and conduct of the Colon Cancer Screening Program.
- (6) The advisory committee shall establish and provide oversight for a colon cancer screening public awareness campaign. The Cabinet for Health and Family Services shall contract with the Kentucky Cancer Consortium at the University of Kentucky to provide the required support. The amount of the contract shall not be included in the base budget of the university as used by the Council on Postsecondary Education in determining the funding formula for the university.
- (7) The Colon Cancer Screening Advisory Committee shall provide an annual report on implementation and outcomes from the Colon Cancer Screening Program and recommendations to the Legislative Research Commission, the Interim Joint Committee on Health and Welfare, the Interim Joint Committee on Appropriations and Revenue, the Governor, the secretary of the Cabinet for Health and Family Services, and the commissioner of the Department for Public Health.
- (8) The Kentucky Cancer Program, jointly administered by the University of Kentucky and the University of Louisville, shall establish a colon cancer screening, education, and outreach program in each of the state area development districts. The colon cancer screening, education, and outreach program shall focus on individuals who lack access to colon cancer screening. The Cabinet for Health and Family Services shall contract with the University of Louisville and the University of Kentucky to provide the required support. The amount of the contract shall not be included in the base budgets of the universities as used by the Council on Postsecondary Education in determining the funding formula for the universities.

Effective: July 15, 2008

History: Created 2008 Ky. Acts ch. 126, sec. 3, effective July 15, 2008.

Legislative Research Commission Note (7/15/2008). There are two incorrect internal references in subsection (2) of this statute that have not been corrected in codification because they are drafting errors, not manifest clerical or typographical errors correctable by the Reviser of Statutes under KRS 7.136(1)(h). However, the reference in subsection (2)(a) to "subsection (1) of this section" should have been drafted as "subsection (1)(a), (c), and (d) of this section" since the deputy commissioner of the Department for Public Health referenced in subsection (1)(c) of this statute serves as an ex officio, not appointed, member of the advisory committee. Likewise, the reference in subsection (2)(b) of this statute to "subsection (1)(e) to (k) of this section" should have been drafted as "subsection (1)(c) and (e) to (k) of this section.

304.17A-257 Coverage under health benefit plan for colorectal cancer examinations and laboratory tests.

- (1) A health benefit plan issued or renewed on or after January 1, 2009, shall provide coverage for all colorectal cancer examinations and laboratory tests specified in current American Cancer Society guidelines for colorectal cancer screening of asymptomatic individuals as follows:
- (a) Coverage or benefits shall be provided for all colorectal screening examinations and tests that are administered at a frequency identified in the most recent version of the American Cancer Society guidelines for colorectal cancer screening; and
- (b) The covered individual shall be:
- 1. Fifty (50) years of age or older; or
- 2. Less than fifty (50) years of age and at high risk for colorectal cancer according to current colorectal cancer screening guidelines of the American Cancer Society.
- (2) Coverage under this section shall not be subject to a separate deductible or separate coinsurance but may be subject to the same deductible or coinsurance established for other laboratory testing under the health benefit plan.

Effective: July 15, 2008

History: Created 2008 Ky. Acts ch. 107, sec. 1, effective July 15, 2008

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Kentucky Cancer Program
Kentucky Cancer Registry
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